

Consultation

The linking and use of biological and health data

1 Do biomedical data have special significance?

We believe that biomedical data have a number of unique characteristics. They have been obtained via legal procedures that partly govern their use. They have personal significance to the donor, and especially with regards to genetic data, the donor's family. They also have legal significance and may impact on a person's rights, over and above their health requirements.

2 What are the new privacy issues?

The new privacy issues encompass several aspects of storing and usage of biomedical data. Because most data is these days brought into contact with other data sets, such as pairing genetic data with epidemiological information, there are numerous emerging issues with regards to how data were maintained and used. As more and more data is combined, privacy will be harder to maintain. There is also a more fundamental issue at stake, which is to do with the extent to which privacy always is a virtue. Progress in medical research will depend, to a certain extent, to allowing different researchers access to data sets. Progress will have to be traded off against the need to protect the participants in these studies.

3 What is the impact of developments in data science and information technology?

The fact that so much data is now available in electronic format carries implications for how it is used and can be used in the future. Increased ability to search and match information mean that privacy will become harder to maintain. On the other hand, this increased connectivity will mean that research can progress at a faster rate. There is a great need for synchronised thinking in the area of data processing and information technology.

4 What are the opportunities for, and the impacts of, the use of linked biomedical data in research?

Linking of biomedical data holds the key to some very great research opportunities. To implement this in a way that doesn't harm patients or relatives is obviously a key priority. In our work with women at risk of ovarian and breast cancer we find that the ability to pair up different types of data is crucial in order to understand cancer progression and patterns of disease. By linking biomedical data we are able to find correlations between various aspects of a person's medical history, which in turn enables us to establish correlation and possible causation.

5 What are the opportunities for, and the impacts of, data linking in medical practice?

We believe there are huge opportunities in data linking in our work. We believe strongly that establishing good databases is key to unravelling the causes of ill health. We have been able to reap the benefits of such large-scale data linking, but we've only started to look at these relationships. We believe that the much-heralded era of personalised medicine will only come about if linking of medical data would become a reality.

6 What are the opportunities for, and the impacts of, using biomedical data outside biomedical research and health care?

The opportunities for using linked biomedical data are almost too numerous to mention. Perhaps an example would suffice. We study the development of ovarian cancer. Currently, there are no good early markers for ovarian cancer. The majority of patients present late and only 40% of patients survive beyond 5 years of diagnosis. We have identified a promising biomarker for ovarian cancer, which might be present in cervical cells that can be obtained on a routine smear test. At present, such cells are discarded without being tested. The population as a whole would greatly benefit if we would be able to use cells from the national cervical screening programme to test our hypothesis.

7 What legal and governance mechanisms might support the ethical linking of biomedical data?

We believe that biomedical data, especially genetic data, require appropriate legal mechanisms in order to protect donors, family members and researchers. In addition, there is need for education and campaigns, in order to address concerns and enable the wider public to see the benefits of this kind of medical research. Increased integration and collaboration between scientists, clinicians, legal scholars and ethicists would facilitate this process.